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ABSTRACT

Children and adults with severe disabilities may have nutritional problems due to the effects of the primary disability (including such syndromes as phenylketonuria, galactosemia, and Hurler's Disease), effects related to medications (including anticonvulsants, tranquilizers, and laxatives), effects of food preferences (restrictive food preferences or hypersensitive oral-facial structures), effects of pureed diets, and effects related to fluid intake. Eight suggestions to help reduce the nutritional and dietetic problems of most severely handicapped children include using a team approach involving nutritionists and dieticians; assessing the child's diet; checking for the nutritional effects of medication and compensating appropriately; working away from pureed foods if possible; ensuring adequate fluids; systematically programing for the child to accept more food, especially a more normal diet; providing good dental care; and promoting movement and activity. (CL)

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Nutritional Considerations for Severely Handicapped Children[1]

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Abstract

All people require adequate nutrition for health and learning. Severely handicapped children are more likely to suffer from nutritional deficits than their non-handicapped peers. This paper discusses some of the reasons that severely handicapped children are at-risk for nutritional problems: (1) effects related to their primary disabilities; (2) effects related to medications; (3) effects related to food preferences; (4) effects related to pureed diets; and (5) effects related to fluid intake. Some basic suggestions for enhancing diet and nutrition are provided and the consideration of diet as part of evaluation and total service planning is recommended.

Nutritional Considerations for Severely Handicapped Children

Welcome. Nutrition has become a controversial topic in education. Unfortunately, educators often belong to one of two groups: (1) those that believe hyperactivity, mental retardation, physical deformity and virtually every other problem of handicapped children can be "cured" by diet, and those that believe that diet has no role in the education of handicapped children. Rather spectacular claims associated with orthomolecular and Kaiser-Permanente diets have produced strong negative as well as positive reactions. This presentation, however, is not about orthomolecular, Kaiser-Permanente or any other controversial dietary regimens. It is about common well documented dietary and nutritional problems of children and adults with severe handicaps. It will define some of these problems and make some suggestions for avoiding them or compensating for them. It is intended to increase your consciousness of nutritional considerations in planning services for severely handicapped children and to make you recognize a need for a nutritional evaluation as part of a comprehensive assessment. The inclusion of a dietician on the transdisciplinary service team may be essential to accomplishing these objectives.

Although additional studies on the nutritional status of handicapped children are needed, some studies have been completed. Palmer (1978) reports information from several studies of developmentally handicapped children. Children included in the research populations of the studies varied; some studies included primarily children with cerebral palsy others included children with a wide variety of developmental disabilities. Among the most frequent problems reported were growth retardation, constipation and nutrient deficiencies. Only about 5 to 10% were free from nutritional problems. In examining diets of these children nutrients commonly found lacking included:

ASCORBIC ACID (Vitamin C)

IRON

FLUORIDE

HIGH QUALITY PROTEIN

CALCIUM

FOLIC ACID

VITAMIN A

VITAMIN D

The full effects of these nutritional deficiencies are difficult to assess, because of the child's primary handicap. Since the severely handicapped child may be expected to exhibit growth retardation, developmental delays and behavioral abnormalities, these phenomena are not likely to be attributed to diet. These may be, however, the manifestations of dietary deficiencies (Zee, 1972).

While dietary deficienicies in themselves may cause significant problems, specific effects of primary disabilities, medications, food preferences, altered texture diets, inactivity and unreliable fluid intake may have additional deleterious effects on severely handicapped children. Unfortunately, many children may suffer from several of these effects and their combined effects may be much more serious than any single problem. To simplify things for today's presentation, they will be discussed individually.

Effects of Primary Disability

Many syndromes associated with severe developmental disabilities also are associated with specialized dietary and nutritional needs. The list of syndromes in this category is long and a discussion of each would be far beyond the scope of today's presentation, but some of the names on the list include:

HURLER'S DISEASE

PHENNYLKETONURIA

GALACTOSEMIA

MAPLE SYRUP URINE DISEASE

SEVERE HYPOTHYROIDISM

PRADER-WILLI SYNDROME

and

LESCH-NYHAN SYNDROME

Two excellent books for information on nutritional aspects of these diseases are Pediatric nutrition and developmental disabilities (Palmer & Ekvall, 1978) and Nutrition

casebook on developmental disabilities (Springer, 1982).

For any of these conditions, however, a general consideration must be kept in mind. Total nutrition must be considered to prevent problems secondary to treatment. For example, if we know a child must have certain foods containing a specific amino acid excluded from his diet, mere elimination of those foods is only the first step. After removing those foods, we must carefully assess the impact of their removal on the child's diet. Often we find the balance of other nutrients is adversely affected, and careful dietary planning is needed to minimize the potentially deleterious effects.

Many conditions without direct nutritional effects, may strongly influence nutrition indirectly. Children with cerebral palsy, for example, require careful dietary and nutritional evaluation. Athetoid children often have increased caloric requirements because of their constant activity. Spastic children, conversely, often require fewer calories than their non-handicapped peers. The need for vitamins and some key nutrients, however, does not decrease proportionately to the decreased need for calories. Therefore, it is important to make certain that adequate amounts of all nutrients are available in the child's diet. In some cases, this may require dietary supplements.

Effects Related to Medications

Medications commonly used with severely handicapped children also may influence nutrition. Many drugs have nutritional side effects and these effects must be considered, especially for the individual who is on long term drug therapy. Much of the information included here regarding specific drugs comes from discussions of drugs and nutrition by Butterworth and Weinser (1980) and by Lipman (1981).

Many severely handicapped children receive anticonvulsant medication. Phenobarbital, Mysoline and other anticonvulsants have been found to reduce folic acid (a B vitamin) in the blood and may cause folic acid anemia. Vitamin B_{12} is also reduced. Symptoms of deficiency of these vitamins may include behaviour problems, forgetfulness, depression, and lethargy, symptoms that may be masked by other mental or physical conditions in a severely handicapped child.

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Anticonvulsants also have been reported to break down vitamin D into inactive substances. This can result in poorly formed and weak bones and teeth. Individuals on long-term anticonvulsant therapy should be carefully monitored. Supplementation of B vitamins and vitamin D may be required.

Tranquilizers are also frequently used among severely handicapped children. In addition to a wide range of other side-effects, tranquilizers also have nutritional effects. They reduce activity and decrease caloric requirements. Often sudden unexplained weight gain or less may betraced to a change in medication. Phenothiazines (e.g., Thorazine, Largactil, Prolixin, Trilafon, Sparine, Mellaril, Stelazine) appear to reduce absorbtion of vitamin B_{12}.

Laxatives are also commonly used with severely handicapped individuals. All laxatives probably reduce absorbtion of important nutrients. Peristaltic stimulents, drugs that work by increasing the speed of gastrointestinal movement probably result in the greatest reduction of nutrients. These include Exlax, Dulcolax, Bisacodyl, and Senna. Intestinal lubricants (e.g., mineral oil) specifically interfere with the absorbtion of fat soluable vitamins (A,D,E and K). Chronic laxative users may develop serious nutritional complications. Reducing dependency on laxatives and elimination of their chronic usage is the ideal solution to this problem. If a laxative must be used, bulk producers (e.g., psyllium) are believed to least interfere with nutrition.

Other drugs also have nutritional effects. Whenever a drug is used or considered, especially for long-term therapy, its nutritional effects should be considered. Drugs that are not truly required should be eliminated, and those that cannot be eliminated must be carefully monitored. Dietary supplements may sometimes be required to compensate for the nutritional effects of long-term treatment. Even vitamins must be used cautiously when administered in therapeutic dosages, high concentrations of one vitamin may increase excretion or breakdown of several others. For this reason, multiple vitamins are sometimes prescribed along with therapeutic dosages of a specific vitamin. Rapid discontinuance of therapeutic vitamins may produce deficiency symptoms, in spite of normal intake.

Effects of Food Preferences

Many severely handicapped children accept only a few foods and refuse the introduction of new tastes and textures. These restrictive food preferences may also lead to nutritional deficiencies. This may be due to hypersensitive oral-facial structures, late introduction of variety in the diet, greater toleration by caregivers than they would show with a non-handicapped child or a variety of other suggested hypotheses. Regardless of the reasons, the effects of the food preferences must be assessed, and if needed, additional foods must be introduced.

Getting the child to accept new tastes and textures may be difficult and the best tactics vary from child to child. Starting early is usually the best plan. Behavior modification techniques of various kinds are extremely useful. A change in environment may be particularly helpful (Linscheid, Oliver, Blyer, & Palmer, 1978). With some children, particularly those who reject varied textures and who show other signs of oral-facial hypersensitivity, I've found tactile desensitization procedures useful. Farber and Huss (1974) and Gallender (1980) describe stimulation procedures that might be used for this purpose. Cooperation between home and school caregivers is essential in getting the child to accept new textures regardless of the specific plan.

Effects of Pureed Diets

Many severely handicapped children and adults are fed pureed diets. This is often done because it is believed that the handicapped individual cannot handle whole foods, because of fear of choking or because of the child's food preferences. Unfortunately, pureed diets are often found to be extremely low in dietary bulk, low in vitamins C and B (and sometimes others), low in protein and high in carbohydrates. Absorbtion of nutrients is variable, since the near-liquid consistency may allow them to pass through the stomach and small intestine very rapidly. Because pureed foods lack bulk, they often cause constipation, requiring laxatives which have further deleterious nutritional effects.

In my own experience, I've found that many of the individuals given pureed foods could handle coarser textures well. With one twelve-year-old girl, who had been fed

nothing but pureed foods, we went directly to whole foods. Although her caregivers had felt she could not eat whole food because she frequently gagged and could not chew well due to severe cerebral palsy, we found that her gagging decreased, her chewing increased and she spilled less food from her mouth when whole foods were given. Although we carefully supervised her, no choking episodes occurred. She accepted whole foods willingly, but other children may require a more gradual transition.

When making the transition from pureed to whole food, a gradual transition is generally best. Food processors are generally better than blenders for this because they generally allow more control over intermediate consistencies. At each stage, keep the consistency uniform: mixed consistencies are the most difficult to handle. Mashed potatoes with peas mixed in, fruit cup in syrup and other mixed consistencies require extremely advanced oral-motor skills.

Normalizing food textures may require longer feeding times, but most children can learn to eat chopped or whole food. Generally this will result in a more varied diet and better nutrition.

Effects Related to Fluid Intake

Many severely handicapped individuals depend on others to provide fluids. Often they cannot communicate their needs and so they become even more dependent. Adequate hydration is essential and we must be certain that fluids are available in sufficient quantities. Without adequate fluids, imbalance of essential electrolytes occurs, which may cause serious illness. Constipation may also result from inadequate fluids.

Warm weather, increased activity, fever, vomitting, diarrhea and illness or injury are all likely to substantially increase the need for fluids. Hydration status should be monitored especially closely and extra fluids offered if any of these conditions exist. Signs of dehydration may include hoarseness, dry lips and tongue, poor skin tone, sudden weight loss, and concentrated urine.

Recommendations

Nutrition is important for every one. It has an important role in health and in learning. Severely handicapped children are even more likely than their non-handicapped peers to suffer from nutritional problems. The following general recommendations can reduce the nutritional and dietetic problems of most severely handicapped children:

1. Use a team approach. Call on dietitians, nutritionists and other experts.
2. Assess the child's diet. Keep a journal: record foods, quantities and how prepared. Be sure to record what is actually eaten not what was prepared.
3. Check for nutritional effects of medications. Request bloodwork to monitor effects. Compensate as needed.
4. Systematically program for the acceptance of more foods. Normalize the diet, whenever possible.
5. Work away from pureed foods, nasogastric feedings, etc., if possible.
6. Provide good dental care.
7. Promote movement and activity.
8. Ensure adequate fluids.

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